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AUTHOR Scanlon, Catherine; And Others
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ABSTRACT

This document notes that chronic illness has replaced infectious disease as the primary health concern facing industrial nations today, and that care for the chronically ill necessarily focuses on management rather than cure and takes place more in the home than in the hospital. It presents a family functioning model for understanding a family functioning around a child's chronic illness, placing special emphasis on the family's meaning process. The model described depicts family functioning as involving six factors in continuous interface with one another in an ongoing cycle. According to this family functioning model, family demands, resources, and meanings combine to produce responses which are either helpful or unhelpful; helpful responses feed back to become additional resources while unhelpful resources become demands. A second model, the Family Intervention Model, is based on the first model and is presented here to help clarify the counselor's tolls in impacting family functioning. This model proposes that, for good family functioning, an intervention model must involve family leadership as a legitimate goal for productive intervention. Types of intervention discussed include supportive, informational, behavioral, cognitive, affective, and historical interventions. A case study involving a family with a chronically ill child is described to illustrate both the family functioning and the family intervention models. (ABL)

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Boston, Massachusetts

ASSISTING FAMILIES IN THE MANAGEMENT OF
CHILDREN WITH CHRONIC ILLNESS

Cathie Scanlon, Doctoral student
Donald Bubbenzer, Ph.D., Associate Professor
John West, Ph.D., Professor
Greg Lofaro, Ph.D., Associate Professor, In memory
Kent State University

Friday, March 17, 3:30-4:15 p.m.
Room 202, Hynes Convention Center

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Assisting Families in the Management of Children with Chronic Illness

Chronic illness has replaced infectious disease as the primary health problem facing industrial nations today (U.S. HEW, 1979). Ten percent of the children in the United States are afflicted (Hobbs & Perrin, 1985). Care for the chronically ill necessarily focuses on management rather than cure; and takes place in the home more than in the hospital. Consequently familial factors are increasingly recognized as important variables in the illness experience (Dohrenwend & Dohrenwend, 1974; Eakes, Haynes, & Feinleib, 1983).

The meaning the family attributes to the illness appears especially central (Antonovsky & Sourani, 1988). Meanings, according to Frankl (1969), are the interpretations given to the events and processes of our lives. As is documented by a growing body of research, a family's meaning attribution system impacts their coping response, which in turn, impacts the actual conditions of the illness. Thus addressing this illness--meaning response--illness system is critical in working with families with a child with a chronic illness.

In this paper we will first describe a model for understanding family functioning around a child's chronic illness, placing special emphasis on the family's meaning process. A second model, based on the first, will clarify the counselor's tools in impacting this process. A case study involving a family with a chronically ill child will be presented to illustrate both the family functioning and the intervention models.

Family Functioning Model

Our first model is developed from the work of McCubbin and Patterson (1982, 1983, 1985, 1988), and depicts family functioning as involving six factors in continuous interface with one another. Family demands, resources, meanings combine to produce responses which are either helpful or unhelpful. Helpful responses feed back to become additional resources; unhelpful responses become additional demands. This is an ongoing cycle.

Demands and resources. The family is normally working to maintain a balance between the demands of the illness (and of life in general), such as treatment regimens, financial burdens, medical crises, and the normal developmental needs of its members; and its resources, such as social support, family cohesion, and members' availability and skills.

Meanings. The balance of demands and resources is mediated by the family's subjective interpretations of events, that is, the meanings ascribed to experiences. For example, one family may interpret a child's chronic illness as a challenge; another family may see it as the "last straw". Meanings are elsewhere described as "beliefs" (Ellis, 1977), "cognitive appraisals"

(Lazarus, 1984), the "family paradigm" (Reiss & Oliveri, 1980), "sense of coherence" (Antonovsky, 1987), "personal constructs" (Kelly, 1955), "meaning in life" (Frankl, 1984), and the "family schema" (Patterson, 1988).

Helpful and unhelpful responses. Demands, resources, and meanings combine to produce a variety of responses. One family may respond by denying the illness; another may seek a second medical opinion or, at another stage, attempt to learn new caregiving skills. A helpful response is one that increases resources, either directly, or via adaptive meanings such as "We are coping". An unhelpful response is one that becomes a new demand, again, either directly, or via negative meaning such as "There's no use in trying".

Feedback. Each response shifts the balance of demands, resources, and meanings, and a next response becomes necessary. The capacity to respond to feedback itself becomes an important resource (McCubbin, Cauble, & Patterson, 1983).

Applications. In review, each component of the model impacts and is impacted by the other components: it follows from this that change in any one component will, in turn, change all other components. While most treatment approaches focus on intervening by reducing demands, increasing resources, etc., here emphasis will be placed on intervening at what appears to us to be the model's point of integration, that is, intervening through impacting meanings. We suggest that a variety of treatment approaches may be used in the service of this objective.

Family Intervention Model

Antonovsky (1987) discusses general components of a meaning process that allows people to cope successfully with stressors such as chronic illness. He labels this view the "sense of coherence" and describes it as a:

global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that 1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; 2) the resources are available to one to meet the demands posed by the stimuli, and 3) these demands are challenges worthy of investment and engagement (p. 19).

In short, people with this meaning signification process tend to see problems as "comprehensible", "manageable", and "challenging".

Friedman (1986) presents a related thesis in his discussion of the need for effective family leadership. Leadership, according to him, is found in the ability to maintain enough distance from the family's emotional whirlwind to keep life goals clearly in mind; to be able to articulate them; and to follow them despite the family crisis. As a result, leaders maintain a nonanxious presence in the system. The centrality of parental leadership for effective family functioning is also subscribed to

by Minuchin (1978), Bowen (1978), Madanes (1983), and others. Hence the development of a sense of coherence through effective family leadership appears a legitimate goal for productive intervention. A brief lexicon of intervention types follow.

Supportive interventions are intended to empower and bring hope. Such interventions may support specific meaning attributions, specific behaviors, and/or the basic worth of the family and its members. Especially important is the ability to articulate and demonstrate positive aspects of the client's lifestyle, thought, and objective and subjective processes. It is the highlighting of the positive that is particularly enabling. The following phrases provide a flavor of some of supportive interventions that enable leadership to emerge and may increase comprehensibility, manageability and challenge in families experiencing chronic illness: "Caring parents", "Almost ready for change", "Very concerned", "Getting to first base" rather than "Getting started", "Using resources available the best you know how".

Informational interventions help the family, particularly parents, to increase their comprehension of problems, processes, and strategies for coping. These interventions may be data-based observations about family dynamics or wisdom garnered from observations of life and other therapeutic instances. Such information is intended to influence meaning often by normalizing behavior and therefore reducing anxiety. Again, the leadership is the usual vehicle for the implementation of interventions.

Behavioral interventions seek to change family meaning systems by getting them to act differently. This may be accomplished through simple directives given either in session or as homework, through interacting with families in different "new" ways, or by the use of paradoxical and more subtle means. For example, if a mother takes primary care of a child who has a chronic illness, the therapist may want to interact more with the father to encourage his active involvement.

Cognitive interventions help family members alter the thoughts or cognitive sets that influence interpersonal interactions and coping strategies. They often bring to light erroneous beliefs, attitudes and values which can then be challenged. In some instances replacement thoughts might include thinking of the stimuli as non-threatening, or at least able to be coped with or mastered. In other situations it may be more appropriate to assist family in accepting the inevitable or in trusting the judgement and abilities of others to provide care. For chronic illness the perception of the problem as being a medical issue versus a behavioral or psychological will have a powerful impact on management strategies used by the family.

Affective interventions aim to manage affect in the family system. This may involve the identification, expression, heightening, suppression, redirection or alteration of feelings. At times it may be helpful to facilitate catharsis, in other instances the goal of affective intervention is energize the session or to dissipate unproductive emotional exchanges.

Chronic illness in families is often a traumatic experience involving intense feelings of anger, hope, and grief.

Historical interventions enlighten the past in ways that explain the present and offer hope for the future. For a family that appears particularly stuck, progress may depend on helping families alter their perception of prior events. Focus may be placed on strengths developed, or assets gained from "enduring" the negative history. Sometimes the attributed meaning that past behavior is responsible for current chronic conditions must be accepted.

Case Study: The Pool Family

The Pool family consists of the mother, Marge, age 34; the son, Chris, age 14; a daughter, Cathy, age 12; and a daughter, Karen, age 8.

Presenting Problem: Chris has recently been released from a major children's hospital where he has spent the past 10 weeks in residential treatment for problems of enuresis and encopresis. He has a mild case of spina bifida. He is able to walk and casual observation would not reveal symptomology. Originally, the medical community had indicated his enuretic/encopretic problem to be organic in nature and related to his spina bifida. However, now the problem has been presented as one that is controllable and success (control of both bowel and bladder) was reportedly achieved during residential treatment. However, since returning home Chris has been enuretic and encopretic on a daily basis both at home and at school.

Current Family Life: Marge is a hairdresser and works five days a week including Saturdays from 10 a.m. until 8 p.m., and sometimes longer if appointments are extended. She attends an aerobics class two evenings a week and frequently spends after work time with a male friend. She usually returns home between 10-11 p.m. The children are alone at home from the end of school until Marge returns. Cathy is in charge of Karen but it appears this after-school time is quite chaotic. There is no established meal period and the children report a great deal of conflict. Much of the conflict is between Karen and the other two children.

Marge reports dissatisfaction with her male friend and indicates she is not getting much from the relationship. He has a "heart condition" and she does not share much with him, fearing that if she upsets him she will aggravate his condition. She also reports being afraid that if she upsets him, he will end the relationship. She reports feeling that her world is out of control, that the children are uncontrollable, and that she would like to find new work. She is uncertain about what she believes about the basis of Chris' enuresis/encopresis problem.

Family History: Marge was married at age 19 to a Vietnam veteran who experienced difficulty with drugs until divorce seven years ago. He was physically abusive with her throughout the marriage and Marge reports getting out of the marriage when this abuse became evident to the children. He is remarried and does

not see the children. She indicates that Karen looks so unlike the other two children that she wonders if Karen has the same father as the other two. There is some teasing in the household about how different Karen looks. Four years ago Marge had a relationship with Max a neighbor who lives a few doors down the street. This relationship ended when Karen reported behavior that indicated Max was sexually abusive with her. The incident was reported to the police, but charges were not filed. Max still comes over to the house to "fix things" (plumbing, etc.) and Marge indicates she needs the help so badly that she does not want to end this support. Max comes during the after-school hours and Karen reports being very fearful when he is there.

Marge's father is deceased, but her mother lives 10 minutes away. She reports a close relationship with her mother although she reports a great deal of criticism from her mother and an older sister. Neither want to assume child-care responsibility.

Possibilities for Intervention.

Supportive Interventions: What behaviors and meanings does the counselor want to support in the family? How should this support be given?

Informational Interventions: What information might the counselor provide to assist in the development of leadership or more functional meaning?

Behavioral Interventions: How should the therapist interact with this family in order to facilitate leadership and functional meaning.

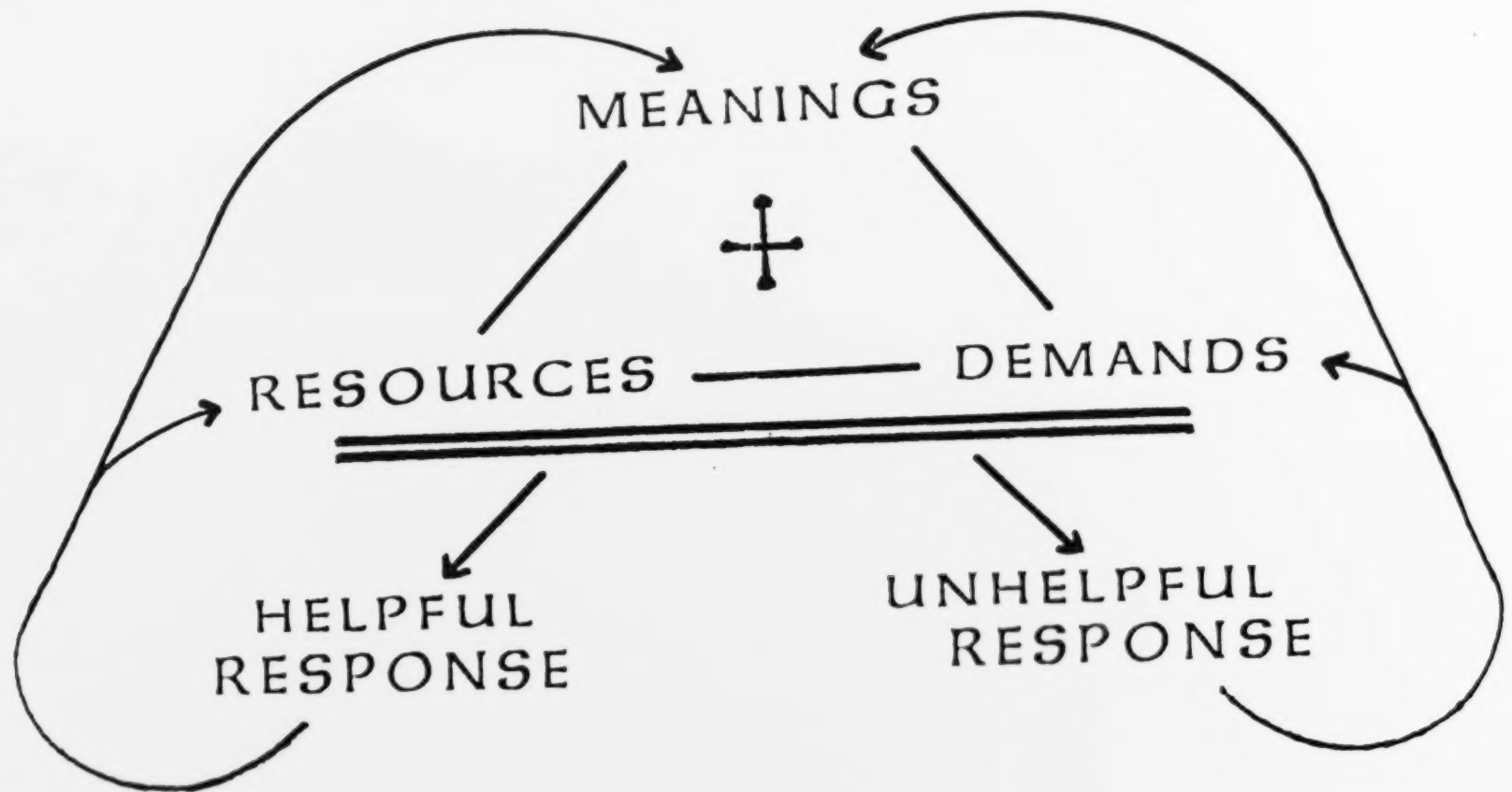
Cognitive Interventions: How might Chris' problems be presented in the context of total family problems to increase comprehension and Mom's leadership potential?

How might the counselor intervene cognitively with Chris to increase the likelihood of Chris being challenged to manage his enuresis/encopresis problems?

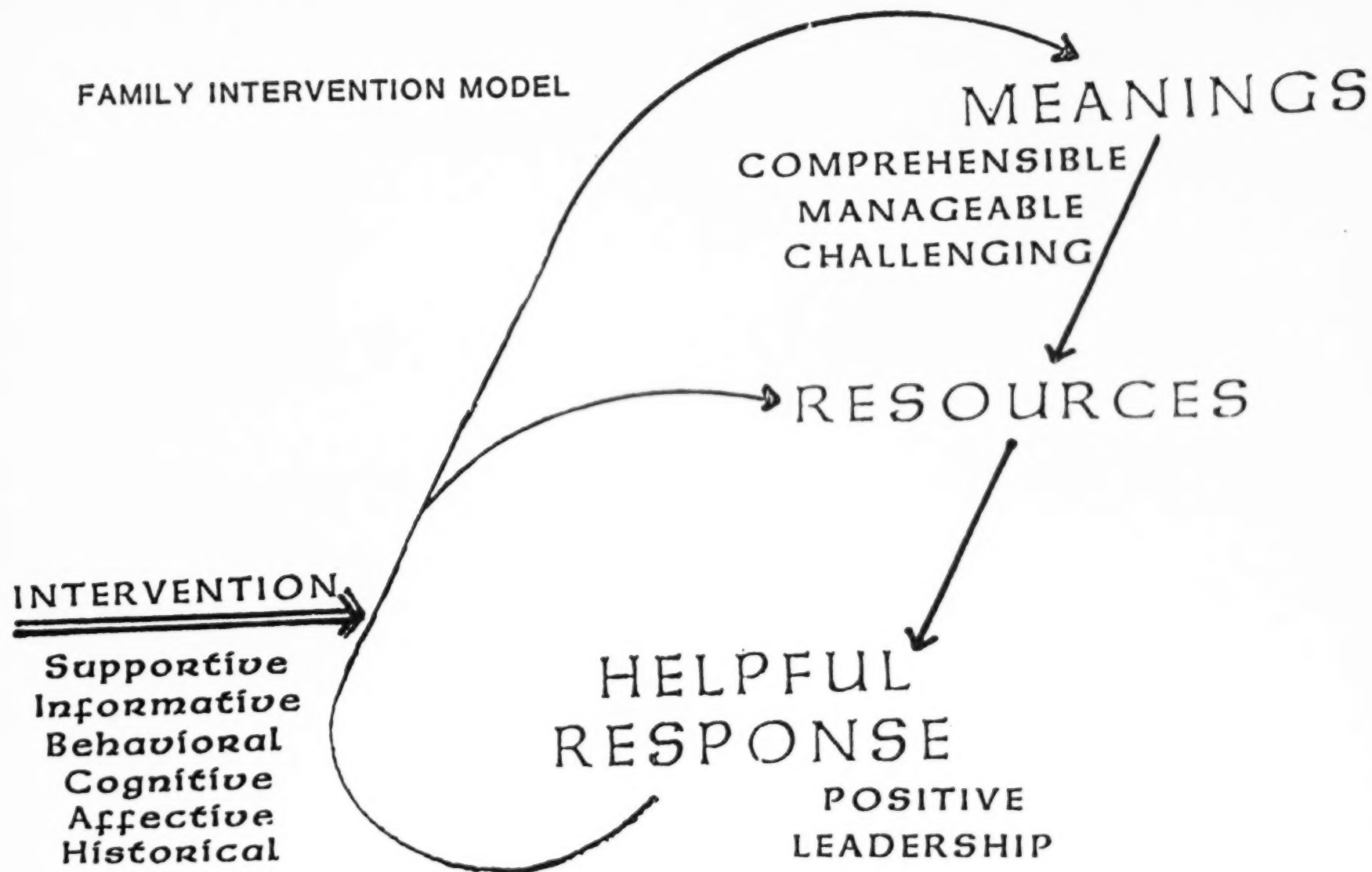
Affective Interventions: Family sessions are described by the counselor as chaotic. What affective interventions might be used to assist in management of the session?

Historical Interventions: What historical connections appear to be worth exploring in relation to Mom's inability to manage the chronic illness? What historical events merit consideration in developing greater leadership potential in Mother?

FAMILY FUNCTIONING MODEL



FAMILY INTERVENTION MODEL



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